

641—1.15 (144) Congenital and inherited disorders. Each occurrence of a congenital and inherited disorder that is diagnosed or treated in an Iowa resident or occurs in a nonresident who is diagnosed or treated in an Iowa facility is a reportable condition, and records of these congenital and inherited disorders shall be abstracted and maintained in a central registry. Congenital and inherited disorder surveillance shall be performed in order to determine the occurrence and trends of congenital and inherited disorders, to conduct thorough and complete epidemiological surveys, to assist in the planning for and provision of services to children with congenital and inherited disorders and their families, and to identify environmental and genetic risk factors for congenital and inherited disorders.

1.15(1) *Who is required to report.* Occurrences of reportable congenital and inherited disorders shall be reported by registrars employed by the Iowa Registry for Congenital and Inherited Disorders, registrars employed by health care facilities, and health care providers involved in the diagnosis, care, or treatment of individuals with reportable congenital and inherited disorders.

1.15(2) *What to report.* The content of the reports shall include, but not be limited to, follow-up data and demographic, diagnostic, treatment, and other medical information. Tissue samples may also be submitted under the authority of this rule.

1.15(3) *How to report.*

a. The department has delegated to the Iowa Registry for Congenital and Inherited Disorders the responsibility for collecting these data through review of records from hospitals, radiation treatment centers, outpatient surgical facilities, oncology clinics, pathology laboratories, and physician offices.

b. Prior to collecting the data from an office or facility, the Iowa Registry for Congenital and Inherited Disorders shall work with the office or facility to develop a process for abstracting records.

1.15(4) *Fetal death (stillbirth).* Each occurrence of a fetal death that occurs in an Iowa resident or occurs in a nonresident who is identified in an Iowa facility is a reportable condition.

a. Providers shall complete the fetal death certificate supplied by the department.

b. Fetal death certificates are to be filed with the department's bureau of vital records within seven days.